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Rheumatoid arthritis: profile of patients and burden of caregivers

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Abstract

Objective: to describe the profile of patients with Rheumatoid Arthritis (RA) and their caregivers receiving care at the Rheumatology Outpatient Clinic of a teaching hospital, and evaluate the burden of the caregivers. *Method:* a cross-sectional study was performed with 41 patients with RA and their caregivers using a questionnaire to identify sociodemographic variables; the Burden Interview Scale and the Stanford Health Assessment Questionnaire. Descriptive analyzes and comparison between clinical-demographic variables and the functional status of patients were performed and the correlation between sociodemographic variables and levels of burden of caregivers was tested. *Results:* there was a prevalence of female patients (87.8%); a mean age of 64.4 years (±12.9); a mean time for the diagnosis of RA of 13.5 years (±8.5), a prevalence of moderate disability (39.0%); lower disability in the Hygiene domain (1.6; ±0.5) and greater disability in the Other Activities of Daily Life (2.1; ±0.6), Reach (2.0; ±0.7) and Grip (2.0; ±0.7) domains. The caregivers were women (73.2%); aged between 17 and 81 years (mean: 46.8; ±15.1); with a high school education (41.4%). The degree of kinship was 56.2% offspring and 36.6% spouses. Eighteen (44.0%) caregivers suffered burden, nine (22.0%) of whom had mild burden and nine (22.0%) of whom suffered intense burden. There was a higher incidence of intense burden among spouses (12.2%) and mild burden among children (12.2%). *Conclusion*: the low occurrence of burden among caregivers may be related to the profile of the patients, who presented good levels of independence for self-care. The profile of caregivers and the prevalence of overburdened spouses and offspring shows the need and importance of the implementation of caregiver training by health service professionals to improve care for RA patients.

Keywords: Chronic Disease. Patient Care. Personal Health Services. Health Evaluation.

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INTRODUCTION

Population aging has resulted in a high prevalence of osteoarticular diseases, such as osteoarthrosis, rheumatoid arthritis and osteoporosis. These illnesses cause pain and restriction of movement, manifestations that can result in limitations in the performance of daily activities, muscular atrophy and reduced aerobic capacity, muscular strength and balance, negatively impacting the lives of the elderly[1,2].

Rheumatoid arthritis (RA) is a systemic, chronic and degenerative inflammatory disease, characterized mainly by the impairment of the synovial membrane of the peripheral joints. It affects approximately 0.5 to 1% of the global population, with a two to three times higher rate in women over 40[3]. The disease is characterized by the symmetrical impairment of the small and large joints, most frequently involves the hands and feet, and has a significant impact on the functional capacity and independence of patients. Physical deformities and pain impair the performance of professional, social and activities of daily living, affecting quality of life and mental health and increasing the risks of negative alterations in psychological parameters[4]. In addition, fatigue, a subjective symptom of low vitality (tiredness, exhaustion, weakness, malaise), accompanied by a reduction in physical and mental capacity, is present in 88 to 98% of patients[5].

The main aims of RA treatment are to reduce pain, joint edema and constitutional symptoms, such as fatigue. It also aims to improve joint function, interrupt the progression of bone-cartilaginous damage, prevent disabilities and reduce the morbidity and mortality associated with RA[4].

The education of patients with chronic diseases and their relatives is an important part of the treatment of such illnesses, as it is associated with greater understanding of the disease and increased adherence to treatment. It therefore falls to health professionals to support patients and their families, promoting health education. Usually the caregivers of patients with chronic diseases are relatives with little experience in care, who assume the task of caring for the patient and being responsible for providing or coordinating the resources required by such individuals, who are dependent, associated with temporary or permanent functional disabilities. These caregivers are considered "hidden patients" and require care and attention from health professionals, as their behavior has an impact on patient treatment[6].

According to the National Health Policy of the Elderly, care can be provided in a formal or informal system. Formal caregivers are individuals who are paid to provide care and have had training to perform such a task. Informal caregivers are family members, friends or neighbors who provide support and voluntary care to those who need it[7].

The activities of caregivers depend on the functional status of the individual receiving care, on the number and duration of tasks requiring supervision, and on their emotional involvement with the patient. The time spent, the type of tasks performed and the dedication to the patient can interrupt or reduce leisure activities, increase stress levels and impose a high physical burden. The task of caring therefore has an important physiological, social, economic and psychological impact on the caregiver, especially with respect to informal caregivers[6].

Family members who become caregivers, who are often unprepared for this role and lack adequate knowledge or support, can suffer impairment of their quality of life, negatively affecting the care provided to the patient. When carrying out the activities associated with caring, caregivers limit their own lives, increasing the likelihood of burden[8].

Considering the above, the aim of the present study was to describe the profile of patients with RA receiving care at the Rheumatology Outpatient Clinic of a teaching hospital, to assess the burden of the caregivers of these patients and to verify if there is an association between the profile of the caregivers and those of the patients.

METHOD

A cross-sectional and observational study with a non-probabilistic convenience sample of patients with Rheumatoid Arthritis and their caregivers receiving care at the Rheumatology Outpatient Clinic of the São José do Rio Preto Base Hospital, on Fridays between August 2013 and April 2014, was carried out.

Patients with RA, as defined by the American College of Rheumatology (ACR) criteria, who were accompanied by their caregivers or family members and had received treated for at least six months were included in the study. Those who arrived at their consultation alone were excluded from the study.

Data were collected during outpatient care, after a medical consultation, during the study period. The instruments were applied by one of the researchers, who interviewed patients and caregivers in a room reserved for this purpose.

An instrument was prepared by the authors for the characterization of patients with RA and their caregivers, which included the variables: age, gender, schooling and duration of the disease.

The functional status of patients with RA was evaluated using the Portuguese version of the Health Assessment Questionnaire (HAQ), validated by Ferraz et al[9]. This consists of 20 questions that evaluate eight areas: dressing, waking up, feeding oneself, walking, hygiene, reach, grip and other day to day activities. For each question, the patient indicates the degree of difficulty experienced when performing the task in the previous week, on a Likert scale of 0 to 3, where 0 represents no difficulty, 1 indicates some difficulty, 2 represents very difficult and 3 means unable to perform the task. The final result is the arithmetic mean of the highest score of each of the eight domains evaluated. The degree of disability is classified as: mild disability (HAQ 0 to 1), moderate disability (HAQ> 1 to 2) and severe disability (HAQ> 2 to 3)[9-11].

Caregiver burden was evaluated with the Zarit Caregiver Burden Scale, validated for the Portuguese language[12]. This questionnaire consists of 22 questions encompassing the areas of health, social and personal life, financial situation, emotional well-being and interpersonal relationships, and can be used to assess the burden of caregivers of individuals with physical and mental disabilities. To classify levels of burden, the following cutoff points were considered: no burden (<46), slight burden (47-55), severe burden (>56)[12-15].

In data analysis, descriptive statistics were used to characterize the sample of patients and caregivers. Data from the Health Assessment Questionnaire and the Zarit Caregiver Burden Scale were scored according to the norms of adapting these instruments for Portuguese[10-13] and analyzed in terms of descriptive parameters.

The distribution of the data was analyzed by the Shapiro-Wilk test ($p<0.05$) and the comparison between clinical-demographic variables and the functional status of the patients was performed by the chi-squared test. The Pearson Correlation Test was used to analyze the correlation between sociodemographic variables and levels of burden of the caregivers. A p-value of less than or equal to 0.05 was considered significant.

The study was approved by the Research Ethics Committee of the institution, under approval number 300.634, dated June 11, 2013, meeting the formal requirements for research involving human beings of Resolution No. 466/2012 of the National Health Council and those of the Declaration of Helsinki. Collection occurred after the reading and signing of a Free and Informed Consent Form by the study participants.

RESULTS

The study included 41 patients with Rheumatoid Arthritis, aged between 27 and 81 years, with a mean age of 64.4 years (±12.9). There was a prevalence of female patients (87.8%). The time since the diagnosis of the disease ranged from 2 to 33 years, with a mean of 13.5 years (±8.5) and a predominance of moderate disability (39.0%). In terms of functional status, patients with RA had lower disability in the Hygiene domain (1.6;±0.5) and greater disability in Other Activities of Daily Life (2.1;±0.6), Reach (2.0;±0.7) and Grip (2.0;±0.7), as shown in Table 1.

Regarding functional status, the results showed that patients with RA required more help from caregivers to perform domestic tasks (25.6%), walk (15.4%), go to a doctor's appointment (10.3%), bathe or take a shower (10.3%) and perform all activities (10.3%). In addition, impairment in daily activities such as going to the bathroom (5.1%), dressing (5.1%) and feeding oneself (5.1%) were observed, limiting the autonomy and privacy of patients, as shown in Table 2.

Table 1. Characterization of patients with Rheumatoid Arthritis. São José do Rio Preto, São Paulo, 2013-2014.

Variables	n (%)
Gender	
Female	36 (87.8)
Male	5 (12.2)
Age Range (years)	
Up to 20	1 (2.4)
From 21 to 40	3 (7.3)
From 41 to 60	10 (24.4)
From 61 to 80	24 (58.6)
Over 80	3 (7.3)
Time since discovery of disease (years)	
Up to 5	7 (17.1)
From 6 to 10	15 (36.6)
From 11 to 15	5 (12.2)
From 16 to 20	7 (17.1)
From 21 to 25	2 (4.9)
From 26 to 30	4 (9.7)
Over 30	1 (2.4)
Degree of disability – HAQ	
Mild disability (HAQ de 0 to 1)	14 (34.2)
Moderate disability (HAQ >1 to 2)	16 (39.0)
Severe disability (HAQ > 2 to 3)	11 (26.8)
HAQ Domain	Mean (±sd)
Dressing	1.7 (±0.7)
Waking up	1.8 (±0.6)
Feeding oneself	1.7 (±0.7)
Walking	1.8 (±0.6)
Hygiene	1.6 (±0.5)
Reach	2.0 (±0.7)
Grip	2.0 (±0.7)
Other activities of daily living	2.1 (±0.6)

HAQ: Health Assessment Questionnaire.

Table 2. Distribution of activities where patients with rheumatoid arthritis require most caregiver assistance, according to the Health Assessment Questionnaire. São José do Rio Preto, São Paulo, 2013-2014.

Tasks	n (%)
Perform domestic chores	10 (25.6)
Walk	6 (15.4)
Be accompanied to a medical appointment	4 (10.3)
Bathe/Shower	4 (10.3)
All activities	4 (10.3)
Shopping	3 (7.7)
Go to the bathroom	2 (5.1)
Put on shoes	2 (5.1)
Get dressed	2 (5.1)
Feed oneself	2 (5.1)

There was a statistically significant correlation between the gender of the patients and the degree of disability (r= 0.4621, *p*=0.0356). However, there was no significant correlation between the age group of the patients and the degree of disability (r=0.02869; *p*=0.8587); duration of disease and degree of disability (r=-0.055175, *p*= 0.7479).

Table 3 shows the characterization of the caregivers. Most were female (73.2%), 41-60 years old (43.9%), with 9-11 years of schooling (46.3%), and were relatives of the patient. A total of 56.2% were children and 36.6% were spouses. The age of the caregivers ranged from 17 to 81 years, with a mean of 46.8 years (±15.1).

The Caregiver Burden Scale showed that 18 (44.0%) caregivers exhibited some degree of burden, with nine (22.0%) experiencing mild burden and nine (22.0%) intense burden. A higher incidence of intense burden was found among spouses and mild burden among children, as shown in Table 4.

Table 3. Characterization of caregivers of patients with rheumatoid arthritis. São José do Rio Preto, 2013-2014.

Variables	n (%)
Gender	
Female	30 (73.2)
Male	11 (26.8)
Age Range (years)	
Up to 20	1 (2.4)
From 21 to 40	15 (36.6)
From 41 to 60	18 (43.9)
From 61 to 80	6 (14.7)
Over 80	1 (2.4)
Schooling (years of study)	
Up to 8	18 (43.9)
From 9 to 11	19 (46.3)
Over 11	4 (9.8)
Degree of kinship	
Son/daughter	23 (56.2)
Spouse	15 (36.6)
Son/daughter-in-law	1 (2.4)
Neighbor	1 (2.4)
Grandson/daughter	1 (2.4)

Table 4. Distribution of levels of burden of caregivers of patients with Rheumatoid Arthritis, according to degree of kinship. São José do Rio Preto, 2013-2014.

Variables	No burden n (%)	Mild Burden n (%)	Severe Burden n (%)
Spouse	7 (17.1)	3 (7.4)	5 (12.2)
Son/daughter	14 (34.1)	5 (12.2)	4 (9.8)
Grandson/daughter	1 (2.4)	-	-
Son/daughter-in-law	-	1 (2.4)	-
Neighbor	1 (2.4)	-	-
Total	23 (56.0)	9 (22.0)	9 (22.0)

There was no significant statistical difference between the level of burden and degree of kinship (children and spouses) ($x^2=0.8761$; $p=0.6453$); duration of disease and level of burden ($r=-0.02400$; $p=0.8816$); degree of dependence and level of burden ($r=0.1506$; $p=0.3472$) of the caregivers.

In contrast, a significant correlation was found between the age of the patient and the burden of the caregiver ($r=0.3487$, $p=0.0254$).

DISCUSSION

The profile of the RA patients evaluated in this study – with a prevalence of women and an age range of 40 to 60 years – is consistent with literature, which indicates that the disease mainly affects women over 40 years of age[3,16]. This has a significant social impact, as, when affecting people of productive age, RA results in limitations that lead to the abandonment from work activities. Such symptoms can affect more than 60% of patients after 15 years of the disease[17].

Also in agreement with literature, the activities where RA patients required more caregiver assistance in the present study were domestic chores (25.6%). This characteristic was associated with the gender of the patients, the majority of whom were female, as the performance of domestic services is a role culturally attributed to women[18].

It was also noted that the loss of functional capacity of the RA patient throughout life is influenced not only by the age and the duration of the disease, but also by the levels of pain and medications in use[19].

It is therefore important that multiprofessional teams implement actions of guidance and health care of these patients, to improve joint function, interrupt the progression of bone-cartilaginous damage, prevent disabilities and reduce the impact caused by RA[4]. In this context, it is recommended that professionals advise patients with RA on the use of joint protection, as domestic activities require flexion movements of the metacarpophalangeal joints, increasing deviant forces and favoring ulnar deviation[20].

Actions in health education should focus on improving the understanding of patients and family members regarding the disease and increasing adherence to treatment, seeking to alleviate its symptoms, such as pain, joint edema and constitutional symptoms like patient fatigue.

Caregivers of patients with RA are therefore highly important for the treatment of the disease and require the care and attention of health teams, as their participation in the health care of the patient will have an impact on recovery from the disease[6].

The caregivers of patients with RA evaluated in this study have a profile compatible with that reported in the literature, namely women with a family relationship, young adults and those without a higher education qualification. Studies have shown that women are the primary caregivers of more dependent and vulnerable people, such as the chronically ill. In the Western context, caring is the duty of the woman and being a caregiver is naturally intrinsic to the female gender. Thus, women become responsible for the care provided to their husbands, children, parents and other relatives[6,21].

The prevalence of family caregivers has been described by other studies[6,22,23]. Caring is related to family intimacy, linked by reciprocity and solidarity, as a form of natural protection provided by family members[21]. It is therefore common for care to be provided by an informal system, including family, friends, neighbors and community members, without remuneration[23]. Among the reasons that lead an individual to exercise the role of caregiver are: moral obligation, cultural and religious aspects, marital status and the absence of other potential caregivers[22].

Family members are considered to be the main providers and coordinators of the resources required by patients with chronic diseases, requiring intense dedication on the part of caregivers due to the evolution and long duration of the disease[6,22]. The care provided by children is attributed to socio-cultural issues and is considered a natural process and the repaying of care received from parents in childhood[23]. There is therefore a reversal of roles from one generation to another, with caregivers seeing the act as a form of obligation[24].

Among spouses, it is common to find one elderly person taking care of another, more dependent elderly partner. This situation demands increased attention from health professionals, as elderly caregivers naturally present functional losses that affect their overall physical, psychological and financial potential and their quality of life, impairing their ability to assist the patient[25].

In addition, older people consider the family their natural habitat and something that is important in all phases of a person's life. The family, therefore, is the entity that best cares for the elderly[26].

Several factors inherent in caring for patients with RA can cause burden in caregivers, whether formal or informal. This burden can be objective when it covers the daily tasks of providing care to the patient, resulting in financial losses, routine disruption, social and professional life; or subjective, when related to feelings, emotions and concerns for the patient[27].

Although the majority of caregivers evaluated in this study did not present burden, negative feelings may occur when caring for the needs of patients with RA. Assuming the position of caregiver implies a change in routine and a restructuring in the organization of tasks, increasing workload and, consequently, overburdening the caregiver[28].

Care can generate stress in family dynamics, causing physical, mental and emotional complications in the caregiver, limiting their health and quality of life[24].

A study with caregivers of chronic patients showed that the more the patient requires care or feels alone, the more distant the caregiver becomes from their family and friends, missing out on opportunities for leisure and social interaction. Therefore, living and caring for a family member with an illness is an arduous task and, depending on the diagnosis, can represent a crisis in the family, generating anxiety, stress, fear and suffering[22].

Aspects such as the symptoms and degree of autonomy of the patient, the treatment performed, and the relationship between the patient and the family caregiver, can aggravate the situation of burden, making it difficult to care for the patient[29]. On the other hand, a greater level of schooling contributes to reducing burden, as caregivers with a higher level of education have a better understanding of the guidelines provided by the health team and carry out care more easily[23].

The results of the present study revealed a significant association between the age of the patient and the level of caregiver burden. This may be associated with duration of RA, which, as it is a chronic disease, requires prolonged dedication on the part of caregivers, increasing the likelihood of burden, especially in the case of family caregivers, who may have greater difficulty in caring for others.

Although other associations were observed in this study, literature points to age as an aggravating factor for the mental health of caregivers. There is evidence of lower stress rates among older individuals, suggesting that, over time, people create more appropriate coping strategies. However, some studies indicate that younger caregivers experience a loss of conviviality with friends, increasing stress levels and the risk of social impact in this population[6,29,30].

Moderating factors such as social support, financial situation and the coping strategies used have an important impact on the mental health of caregivers, and may harm or relieve them from such impacts. A study with elderly caregivers indicates that participation in weekly caregiver groups contributed to the reduction of depression and, as a consequence, there was an improvement in the quality of care provided, generating positive changes in the behavior of the elderly and their quality of life[31].

According to Pedreira and Oliveira[32], families with a better economic and emotional structure tend to act more effectively in their relationships with dependent individuals. The authors emphasize that burden may vary according to the cognition and behavior of the elderly person, the family relationship between the caregiver and this person, and the support provided.

Limitations of the present study include the lack of study of the emotional, social or occupational aspects of caregivers of RA patients; and the fact that the patients and caregivers evaluated were from a single health institution. Although it is a regional referral service, the realization of new studies covering other health services will allow a better understanding of the profile of patients with RA and their caregivers, and deepen the understanding and discussion about the factors that cause burden in these caregivers.

CONCLUSIONS

The profile of the patients with RA observed in this study (women, mean age 64.4 years, average time of diagnosis of 13.5 years, predominance of moderate disability, less disability in the hygiene domain and greater disability in the domains Other Activities of Daily Living, Reach and Grip) and their caregivers (women, mean age 46.8 years, complete high school education, children or spouses and no burden) is similar to that reported in the literature.

The fact that most caregivers in this study did not exhibit burden may be related to the profile of the patients, who possessed high levels of independence in terms of self-care.

The prevalence of spouses and children among caregivers with burden strengthens the thesis that care is related to family intimacy, constructed through traits of reciprocity and solidarity.

The identification of the profile and functional loss levels of RA patients in outpatient care and the levels of burden of their caregivers helps health professionals to adjust their care strategies, seeking to attenuate the symptoms and impairment caused by RA, improving the clinical conditions and quality of life of patients.

In addition, it allows the implementation of programs of emotional and occupational support, capable of meeting the demands of caregivers, minimizing the effects of burden and improving the health and quality of life of such individuals.

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